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The AIDS Project

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"Change Is The Only Constant"

by Michael Martin

We're back! "In The Affirmative" is back and now a monthly newsletter. Towards the middle of each month we'll be publishing articles and information we hope you find useful as a client of TAP and as someone, like me, who is HIV-positive or has AIDS. We'll try to keep you up-to-date on things of interest and importance to people with HIV/AIDS through this newsletter, which is put together by clients and staff at TAP. As always, if you'd like to contribute or have ideas for articles, just contact "In The Affirmative" at The AIDS Project.

There have been a lot of changes at TAP since our last issue, most of which I'm sure you know, but just in case, I'll run some by for you. The most notable changes are those of staff changes. Gone, but not forgotten, are Deborah Shields (Administration), John Bean (Case Management), Terry Dubois (Accounting), Eve Cimmet (Administration), Linda Paffinger (Education) and Doreen Merrill (Administration). And soon to leave are Jane O'Rourke (Case Management) and Willy Willette (Outreach). There have been and will be replacements and additions to the staff and I have included a listing of TAP's staff and Board of Directors on page two. You can't tell the players without a program, so they say.

Among the changes, too, are the addition of more support groups for people infected and affected by HIV/AIDS, and I've included a listing of all these groups on page eight. In addition, TAP has opened an office in York County to better serve clients. There are also five new members to the Board of Directors, including two who are clients of TAP. That makes the number of clients on the Board total four.

Still, with all the changes (and change truly is the only constant in life) The AIDS Project continues to provide service to clients, education to the community and leadership in the state of Maine around issues of HIV/AIDS. The AIDS Project continues to strive to do all of these jobs even better. The Client Advisory Board continues to meet every second Thursday of the month so that any and all clients can come and express their feelings and ideas to TAP staff and other clients. So, despite the changes that have happened and will happen, TAP continues to serve and grow.

Since Deborah Shields resigned Paul Draper has been the Acting Executive Director while the Board of Director's Executive Search Committee works to find a new Executive Director. The first search did not come up with a new Executive Director, so the search is now reopened. As one of the seven members of the Search Committee, I can safely say that we were all disappointed that the first search was not successful, still we're committed to finding an excellent person to fill the job of Executive Director. It is not unheard of for a search to have to be reopened and so, in the interim, Paul will continue as Acting Executive Director and the business of TAP will go on.

Other changes at TAP involve on-going discussions with other organizations to form (continued on page two)
(continued from page one)

collaborative efforts to improve and coordinate services and care for people with HIV/AIDS. Also, TAP is looking to the future and planning for whatever the future may bring through changes in things like state and federal funding.

News and information about TAP will be more available through this monthly newsletter to clients and through the restart of TAP's other newsletter sent to TAP's friends and donors.

All in all, lots of changes, but also, lots of work and effort to make sure TAP stays on target. To make sure clients are well-served, a few months ago, a Case Manager On Duty system was set up to make sure that no matter when a client calls during regular business hours, his or her call will be directed to someone who can be helpful. And so that more clients can have an opportunity to attend the Client Advisory Board's meetings, the meetings will be held in York County or Androscoggin/Oxford County occasionally, in addition to meetings in Portland.

The goal is always the same, the mission still vitally important: to serve people infected and affected by HIV/AIDS, to provide education to the general public, and to lead in Maine's efforts to confront HIV/AIDS. Change, however, will continue to be a constant as The AIDS Project is a living, breathing organization growing and adapting to the needs of the present and future. As the number of clients grows and as clients live longer, the future promises the need to be flexible, yet determined.

So, sure there will always be changes, and sometimes changes can cause some disruptions; still, The AIDS Project has come through ten years of this disease and will continue for many, many more. With input from clients, community, staff, and board members, the work of TAP will constantly be assessed and adapted with a constant purpose and mission. And in this light, change can be a very good thing indeed.

In The Affirmative is a monthly newsletter published by the clients and staff of The AIDS Project for people living with and affected by HIV/AIDS. Letters, articles or other submissions should be sent to: In The Affirmative, c/o The AIDS Project, P.O. Box 5305, Portland, ME 04101 or call 207-774-6877. Submissions can be printed anonymously as long as the person submitting the material includes his or her name and phone number for verification.

News, information and features are as up-to-date as possible prior to publication. Any medical information included in this newsletter is submitted for the reader's information only, to be used as the reader so chooses.

Contributors to this edition of In The Affirmative include:
Paul Draper  Jane O'Rourke  Jill Tacy
Mike Martin, Editor
Good afternoon, I'm Mike Martin. Thank you for being here today. I'm here today to share with you the concern and the compassion that we all have as we take note of the impact of HIV and AIDS, here in our community, and in our world. We've all been touched by this devastating disease in some way.

I, myself, am HIV-positive, having tested positive nearly eight years ago. My own involvement in the AIDS community in Maine includes working on a client newsletter at the AIDS Project here in Portland, chairing the Client Advisory Board at the AIDS Project and recently joining the Board of Directors of the AIDS Project. I am currently involved in an experimental drug study going on at the AIDS Consultation Service at Maine Medical Center and, most importantly, I attend an HIV support group on Thursday evenings. I tell you all this, just to let you know part of who I am and why I am here today.

The theme of this year's World AIDS DAY is "Shared Rights and Shared Responsibilities" and as I sat down to figure out what I would say to you today, the word that stood out to me in today's theme is the word "Shared." And so I have some thoughts to share with you this day.

I learned two great lessons in life from my family, and I have time to tell you one of them. It is a lesson, an ideal, that I learned not from a lecture but from the actions of my parents, grandparents, aunts and uncles. It is a simple lesson, with complex applications. The lesson is simply this, there is always room at the table.

When it was mealtime in my home and the homes of my relatives, everyone, family, friends, neighbors, whoever were invited and encouraged to sit down and share the meal. I never heard anything like, "We're going to eat now, you'll have to go home." Or, "I'm afraid we don't have enough to go around, so we can't invite you to dinner." When it was mealtime, there was always room at the table.

This was not because we had more money or more food that the next family. It was because my family believed that if we shared there was always enough to go around. So there was always another chair or stool to pull up to the table, more potatoes to be boiled if needed, and plenty of goodwill to around.

It is a lesson through deed that my family passed on to me and my brothers. It is a lesson that has greater meaning that just mealtime. It is a philosophy about life and our place in the community. That if we share, the rights and responsibilities of life, there will always be enough to go around and room for everyone at the table.

As we here in Maine debate the issue of rights, I would say that I learned from my family, that if we share, there is room for everyone to have those rights. That these rights are not a finite quantity to be parcelled out to a select few, but to be shared by everyone at the community's table.

And that the responsibility we all have is to share; to make sure that everyone is invited to the sit at the table.

And when we talk about people with HIV and AIDS, and people affected by HIV and AIDS, there are plenty of responsibilities to share. There are needs and wants that we all can help to provide. How we do that; how much time and energy we devote to this difficult and draining disease is, in large part, determined by our own sense, our own individual determination of what we can do to make sure that those infected and affected by HIV and AIDS are literally and figuratively invited to sit at the table.

It is within all of us to do what we can to help, to make room, and to share the blessings of life, and liberty, and pursuit of happiness. If we share, there are enough of these things to go around. But it takes a conscious effort to determine how we do this as individuals and as a community. It is about thinking and feeling. A combination of our heads and our hearts.

There is room at the table for everyone to share as we struggle to deal with HIV and AIDS. Many are already doing their share and many are doing more than their share. We have a truly amazing community brought together by this awful disease. I am pleased and proud and touched by the many people I have met who are infected and affected by HIV and AIDS. I am saddened by the death of my friends, from AIDS, yet I have been greatly impressed, too, with their handling of the disease. I am particularly touched by those families and friends who have come together to help those with AIDS live and die with dignity. And I am profoundly moved by the AIDS Quilt, the likes of which had never happened before; a living memory of those who have died that reminds us and our community, our nation and the world of the importance of all who have been taken by AIDS.

And so I would say that when it comes to shared rights and shared responsibilities, we all have the responsibility to determine what it is we can do, and the right to say, this is all I can do. We have the responsibility to help others live a good life, and the right to live a good life ourselves.

As for that wonderful lesson I learned from my family that there is always room at the table, I would also like to say that I believe that lesson applies in heaven. If I use just my head, I'm not sure there is a heaven, but in my heart, when I feel the love and caring and affection that I have for all the people in my life who have died, I do believe that there is a heaven. There must be a place where those who have gone from this earth have met up in peace and understanding. Where my grandparents are together, where my friends who have died from AIDS are together with their families and friends, and where, if heaven is truly heaven, there is room for everyone at the table, regardless of all those things that separate us here on earth. For heaven truly is not heaven, if it is just another place where ignorance and intolerance exists; if it is just another exclusionary club. No, it must be a place where there is always room at the table for one more.
Services for People With HIV/AIDS

In the Windham area:
- Free haircuts for PWHIV/AIDS.
  The John Lawrence Salon will provide free haircuts and free transportation, if needed, to the salon. This can be done on Mondays and Wednesdays only. To set up an appointment and a ride you can call the salon at 892-2636.

In the Greater Portland area:
- Babysitting for children with HIV/AIDS.
  Betty Bessette, a grandmother, is willing to babysit up to 5 children at her home on a daily or weekly basis (daytimes only). Betty charges $5 a day or $25 a week, a nominal fee to buy supplies for the children. In the past Betty has babysat for blind children and she is trained in First Aid and CPR.
  To contact Betty call 878-5243, if Betty is not there you can leave a message with her daughter and Betty will return all calls. Betty tells us that she has lots of patience and loves children. Her home is located in a complex called "Woodwind" near the Northgate Shopping Center.

In the Greater Portland area:
- Home Communion Visits for PWHIV/AIDS.
  Jim DiNapoli, a member of the West Scarborough United Methodist Church, is available to provide communion to anyone with HIV/AIDS on the first Sunday of each month. Communion and/or prayers for clients, significant others and their families will be brought to clients' homes by Jim. This service is available to anyone who wants it, regardless of religious affiliation. Client confidentiality will be respected. If you would like to partake of this service, call Jim DiNapoli at 775-7231, Extension 129 between the hours of 8:30 a.m. and 5:00 p.m. or you call the West Scarborough United Methodist Church office at 883-2814 and leave a message on the answering machine.

A Letter from Getty Payson, TAP Case Manager for York County

April 1, 1996

Dear York County Clients,

We now have an office in Kennebunk! It is located in the Lafayette Center in downtown Kennebunk on Route 1. The new office is great and I am very excited to be here. I am even happier to be more accessible to you.

From I-95, take the Kennebunk exit, after the toll, take a left and at the next stop sign, take another left. You will be on Route 35 heading south. Continue until you come to a fork, go right, towards Wells. You will see a sign for Color Copy Design, take a right just before this building and park in the parking lot. From the parking lot, go around to the right side of the building on the river side. You will see a sign that says "Storer Building." Go in this door and take the elevator to the second floor. We are located in the suite of offices called "Southern Maine Business Center." There is a waiting area inside the door.

If you are coming from Route 1, you can't miss the Lafayette Center. It is a large brick building on the river. It used to be an old shoe shop. Tom's of Maine is in this building. Turn onto Water Street and take a left after Color Copy Design, then follow above directions.

I am often out of the office doing home visits, but please leave a message on the answering machine, which is also a fax machine. If you have any questions, please do not hesitate to call me.

Finally, a reminder about the support group at St. Mary's in Wells. I have received many requests for a support group, but so far only one person has attended. Please come if you can. I would appreciate feedback concerning why you aren't coming. If there are other places or times that you would prefer holding the group, please let me know.

Wishing you peace,
Getty Payson
Critical Information about the Availability and Use of Indinavir (Crixivan®) and Ritonavir (Norvir®)

As you may have heard, the two most powerful protease inhibitors, ritonavir and indinavir, have been approved by the FDA. We believe these drugs are the most important compounds yet for the treatment of HIV infection. However, there are important issues about how to use them and important information about how to access them.

The most important message about the use of protease inhibitors is that you may have only one chance to get the maximum benefit from these drugs. If they are used correctly, they may produce a large and long-lasting benefit. Used incorrectly, they may only produce a short-term benefit followed by the rapid development of multi-drug cross-resistance, rendering the whole category of protease inhibitors ineffective.

Access Issues: Ritonavir is routinely available by regular prescription from pharmacies. Questions about payment assistance and reimbursement for ritonavir call 1-800-659-9050. Indinavir supplies might not be able to meet the demand for the next six months, so this drug will only be available through a special ordering system. You or your physician will have to visit Stadlanders Pharmacy at 1-800-927-8888 to get the drug. Special arrangements have been made to make this possible in all states, including places where Stadlanders is not generally active. Some public hospitals may make special arrangements on their own with the company, but it is best to assume that you will have to order through this special number unless you are notified otherwise by your doctor. People without insurance and who are unable to pay for indinavir should call 1-800-927-8888 to receive assistance on reimbursement sources or to receive the drug free.

Who Should Use These Drugs? Both drugs were approved for the treatment of HIV infection in adults when antiretroviral therapy is warranted. Early studies show that ritonavir increased survival in people with advanced disease. Some studies have not yet been tested in people with early disease. The recommended dose of ritonavir is 600 mg twice daily.

The data supporting the use of indinavir is limited to studies which showed large improvements in surrogate markers (viral load and CD4+ cell counts). The indinavir data spans both advanced and early disease. It is still unknown whether indinavir will delay disease progression or prolong survival, but surrogate marker improvements of the type demonstrated by the drug have been linked to such benefits in other studies. These studies are ongoing and results should be known by early 1997. The recommended dose of indinavir is 800 mg every eight hours.

What About Side Effects? Side effects for ritonavir include nausea, headache, diarrhea, vomiting, weakness, and elevated liver function tests. Although these effects were reported widely in early trials, this may have been due to poor liquid formulation of the drug. It has since been replaced by a gel cap formulation, which avoids some of the unpalatable taste associated with the liquid formulation. It is unclear how frequently these side effects occur with the new formulation.

Indinavir has generally been well tolerated in clinical studies. Some of the side effects that have been noted in a small minority of users include nausea, headache, diarrhea, vomiting, insomnia, weakness, abdominal pain and back pain. One of the more serious side effects has been referred to in the media as "kidney stones." This description may be misleading, since only a very few people have actually seen anything like a small kidney stone appear. The side effect occurs in the form of flank pain, or pain in the urinary tract. This pain is caused by small undissolved crystals of the drug which are being removed by the kidneys. In most instances, this problem has occurred in people with advanced disease who were dehydrated. The solution seems to be to make sure a person using the drug takes adequate liquids along with the drug. People who take indinavir should drink at least 48 ounces of water (about 8 glasses) a day to reduce the risk of developing kidney stones. Indinavir should be taken one hour before or two hours after a meal to increase absorption. Foods with no fat such as toast (no butter), skim milk and corn flakes should not affect the absorption of indinavir and can be taken at the same time. Additionally, ddl (Videx®) should be taken on an empty stomach one hour before or one hour after taking indinavir.

Major Issues To Consider: How To Use These Drugs. All protease inhibitor drugs run the risk of triggering the development of viral resistance. Moreover, once people become resistant to one of these drugs, they are likely to be resistant to the others as well. The existing studies of indinavir show that this problem can best be minimized by adhering to the following guidelines:

• Stick to the recommended dosage at all times; reducing the dose, or skipping doses increases the risk of developing resistance. If side effects occur, it is better to temporarily stop using the drug than to lower the dose. If it becomes necessary to stop and then restart the drug, start again at the full normal dose - do not start with a reduced dosage.

• Use these drugs as part of a 3-drug combination; existing data suggests that both monotherapy use and 2-drug combinations are less effective in suppressing viral load and increasing CD4+ counts. The 3-drug combinations should also minimize the development of viral resistance.

• Combine with drugs which are known to be active; drugs which have been used for a very long time and which no longer appear to be working are not ideal candidates for playing a role in a 3-drug combination.

Drug Interactions: People using ritonavir should be extremely careful to read the package insert, which lists dozens of drugs which can have interactions with ritonavir. This includes many drugs commonly used by people with advanced HIV disease. This list of potential drug interactions with ritonavir is too large to list here, but it warrants great caution in the use of this drug. People who take indinavir should not use the following drugs: terfenadine (Seldane®), astemizole (Hismanal®), rifampin (Rifadin®, Rifamate®, or Rimactin®), cisapride, triazolam (Halcion®), or midazolam (Versed®). Additionally, for people taking indinavir and rifabutin (Mycobutin®), the dose of rifabutin should be decreased. People taking indinavir and ketoconazole (Nizoral®) should consider the effect on their dose of indinavir.

For a complete list of possible interactions with these and other HIV drugs, call the Project Inform hotline at 1-800-822-7422, and ask for the drug interaction fact sheet, or download it from our website at http://www.projinf.org, or (text only) http://www.hivnet.org.
Positively Social (P.S.) is a group by and for people with HIV/AIDS. This is your chance to socialize and enjoy the company of others with HIV/AIDS.

P.S. holds monthly socials on the 2nd Friday of each month at 7 p.m. Socials are held at the Williston West Church at 32 Thomas Street in Portland. These socials are pot-luck affairs full of fun and fellowship.

Positively Social is also sponsoring a spring retreat at Pilgrim Lodge in Litchfield, Maine on May 2, 3, 4 (Thursday through Saturday). This is a retreat with workshops on issues important to people with HIV/AIDS and is open to anyone with HIV/AIDS. Many people have already signed up and there is still room for many more. The cost of the retreat is $40. There are a limited number of scholarships available and many AIDS organizations are willing to sponsor participants, as well. The cutoff date to register for the retreat is April 20th, so you need to hurry.

For more information about Positively Social and/or the Spring Retreat you can write to: P.S., RR 2 Box 177A, Alfred, ME 04002 or call (207) 499-0166.

The AIDS Project presents:

**The Women's Network**

A monthly lecture series and discussion group for women in the HIV Community.

Join us on the third Tuesday of the month from 12:30 to 2:30 p.m.

At The AIDS Project, 615 Congress St. - Sixth Floor in Portland.
Brown Bag lunch, bring your own.
Dessert and beverages provided.
Child care and transportation available.
(please call 774-6877 to request.)

Next Meeting:
May 21
HIV and Motherhood
Lisa Carson and other guest speakers

▲Look for an insert in this newsletter on the Maine AIDS Walk to be held on Sunday, May 5th at 1:00 p.m. at Chevrus High School, 267 Ocean Avenue, Portland or at many other sights in Maine. Call 874-0091 or 1-800-416-8769 for more information.

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**Medicaid to Cover Liquid Dietary Supplements**

Peaches Bass of the Maine AIDS Alliance passes along this information concerning a court settlement in the State of Maine concerning persons with HIV/AIDS. In a November decision, a settlement was made in the case of an AIDS patient (who has since died) and the Maine Department of Human Services which calls for the Department to provide Medicaid coverage for liquid nutrition.

The settlement provides for a class of persons, in this case persons with HIV/AIDS. Under the agreement, the Medicaid recipient must be either currently malnourished (documented) or at significant risk for malnourishment secondary to an underlying medical condition (documented). Coverage is subject to prior approval by the Department and must be documented by a physician prior to approval. Prior to approval a physician must document attempts to employ other oral measures to correct the risk/condition or document that other oral measures are contraindicated and why. The Department must also review pending requests of this type up to the time of the settlement.

The Department paid the plaintiff $300 and covered filing fees and attorney fees for the plaintiff. Neither party admits liability or concedes any issues before the court.
**upcoming events**

You can make a world of difference!

### AIDS SUPPORT VOLUNTEER TRAINING

**IN LEWISTON - AUBURN**

- Provide Transportation
- Respite Care
- Help with Food/Delivery of Meals
- Buddy Program
- Home Maintenance/Cleaning
- Child Care
- and more....

For more information call:

- AIDS Coalition of Lewiston-Auburn
  (207) 786-4697 or
- The AIDS Project (Lewiston-Auburn)
  (207) 783-4301

**Sponsored by:** Merrymeeting AIDS Support Services, The AIDS Project, and the AIDS Coalition of Lewiston-Auburn.

A collaborative project of the Community AIDS Network of Auburn & Lewiston, citizens and providers working together to foster community awareness.

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**No Such Thing As A Free Lunch Don't You Believe It !!!**

Every Thursday at Noontime there is a free lunch for people with HIV/AIDS at The AIDS Project's offices in Portland. So there you have it. There is such a thing as a free lunch!

A nutritious and delicious lunch is served every Thursday for both clients and staff of The AIDS Project. It's a good meal, good company and great fun. So come on up to the sixth floor and enjoy.

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**book notes**

**THE HIV DRUG BOOK**

There is a new book on the market from Project Inform, one of the nation’s leading AIDS service organizations. It is a comprehensive and illustrated resource book filled with information on the most used treatments for HIV/AIDS. It lists and describes all the drugs used by people with HIV and tells about the drugs’ side effects and interactions.

The HIV Drug Book is a valuable resource for people with HIV/AIDS, their caregivers, friends and family members. It lists all the drugs, all the treatments, includes color photos of the different drugs and offers sound advice on taking charge of your health.

For a donation of $50 of more to Project Inform they will send you a copy of The HIV Drug Book on request or you can get this nearly 700-page book at any bookstore. If your favorite bookstore doesn't have it, ask them to order it, so that they will become aware of this great resource. The book costs $16.00 and the ISBN number is 0-671-53518-8. All royalties from the sale of this book benefit Project Inform.

For more information contact Project Inform at:

1-800-822-7422

and ask to be put on their mailing list to receive other free updates on HIV/AIDS news and treatments.

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**client meeting**

The next meeting of the Client Advisory Board will be on May 9 at 1:30 p.m. in the large group room at TAP's offices in Portland. Meetings are held on the 2nd Thursday of each month.

The Client Advisory Board is made up of any and all TAP clients who wish to attend these meetings. The meetings usually last about an hour and a half and they follow the free Thursday noontime lunch open to all clients and staff.

Meetings are broken down into three segments. The first segment is for the staff to bring up information and concerns. The second segment is for clients to bring up their concerns and questions. And the third segment is a clients only time for clients to express their concerns and needs in a confidential setting.

The success or failure of the Client Advisory Board rests in the hands of us clients and I encourage any and all clients to attend these meetings and to speak up about any and all concerns or compliments you may have concerning The AIDS Project.
Mondays
5:30-7:00 p.m. - HIV and Substance Abuse Recovery
A safe space for people living with HIV and in the process of recovery from alcohol and drug addiction. Small Group Room, TAP.

Tuesdays
10:30 a.m.-Noon - HIV Infected and Affected Drop-in Support Group
A place for both persons infected and affected to express feelings, share experiences and receive support. Large Group Room, TAP.

(2nd/4th Tuesdays)
Living Well
A group for people living with HIV that focuses on quality of life and empowerment. Contact Sandy Titus at Stratogen Health Care at 878-0017 for location and time.

6:00-7:30 p.m. - Grief and Bereavement Support Group, cosponsored by Peabody House and TAP
An open support group for anyone affected by AIDS-related loss. First Parish Unitarian Church, 435 Congress Street, Portland.

Wednesdays
7:00-9:00 p.m. - Videos and Safer Sex for Men
An open sex discussion group for gay, bisexual and questioning men of all ages. This safe and confidential educational group will focus on safer sex today, barriers to safer activity and skills development for healthier choices. Call John Holverson at 774-6877 for more information. Large Group Room, TAP.

Thursdays
Noon - Open Client Lunch
Informal gathering of TAP staff and clients. Large Group Room, TAP.

1:30-3:30 p.m. - (2nd Thursdays) - TAP Client Advisory Board Meetings
A forum for clients to offer suggestions and express ideas. Large Group Room, TAP.

5:30-7:00 p.m. - People Living with HIV
Drop-in support group open to anyone with HIV/AIDS. Large Group Room, TAP.

Other Support Groups - Other Counties
Androscoggin/Oxford Counties
Tuesdays, 1:30-3:00 p.m. - People Living with HIV
Drop-in support group. 3rd Tuesdays of the month also open to partners. Group Room at TAP Office at 1 Auburn Center, Auburn. For more information contact Diana Carrigan at 783-4301.

York County
Friday, 10:30 a.m.-Noon - HIV Infected and Affected Drop-in Support Group
A meeting for both persons infected and affected by HIV/AIDS. St. Mary's Community Parish, Eldridge Road, Wells. For more information contact Getty Payson at 985-8199.

TAP is also working to establish HIV-positive support groups for recovering IV drug users, women, persons with psychiatric disabilities and more rural PWHIV's. Any suggestions or questions about TAP Support Groups, please contact Randy May at 774-6877.

AIDS - Since the beginning:
476,899 Cases in the U.S.,
295,473 Deaths;
In Maine: 712 Cases of AIDS,
335 Deaths.

National Statistics as of 6/30/95
Maine Statistics as of 12/31/95